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**Parental Stress Measures and Language Intervention Training for
Parents of Children with Autism Spectrum Disorder**

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Parents of Children with Autism Spectrum Disorder**

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Dedication

This project is dedicated to people with autism and their families, especially those who participated in UT Project SKILLS.

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Abstract

Parental Stress Measures and Language Intervention Training for Parents of Children with Autism Spectrum Disorder

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Parents of children with autism spectrum disorder (ASD) have been shown to report higher levels of stress than parents of typically developing children and parents of children with other disabilities (Hayes & Watson, 2013). UT Project SKILLS is a parent-directed speech and language intervention that directly targets children's social communication skills and indirectly targets parental self-efficacy and resilience. The goal of the present pilot study is to characterize parenting stress reported by parents participating in Project SKILLS and to examine change in stress from pre- to post-intervention. 56 parents of children with ASD participated in the study and completed the parental stress scale. 19 participants completed both the pretest and the post-test surveys. Participants reported stress levels within one standard deviation of all parents who participated in previous work examining parenting stress utilizing the parental stress scale. Three distinct patterns of change emerged: decreased stress, no change, and increased stress. The study has a number of limitations that prevent generalization to broader populations. However, the results contained clinical implications and highlighted a need for future research in the area.

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Chapter 1: Introduction

According to the American Speech-Language and Hearing Association, autism spectrum disorder (ASD) is a neurological developmental disability characterized by marked deficits in communication and social abilities (American Speech-Language and Hearing Association, 2017). Children with autism often display problems with joint attention, play, understanding gestures and words, using gestures and words, following directions, and imitation. Due to these deficits, children may use challenging behaviors to communicate their wants and needs (ASHA, 2017), thus increasing the stresses of parenting. Researchers at the University of Alberta conducted a meta-analysis and established that parents of children with autism consistently report significantly higher stress levels than parents of typically developing children and parents of children with other developmental disabilities (Hayes & Watson, 2013).

Past research in the area of ASD indicates that intensive early intervention significantly improves the prognosis for children (Turner, Stone, Pozdol, & Coonrod, 2006). The National Research Council (NRC) conducted a thorough review of treatment for ASD and recommended that children with ASD receive a minimum of 25 hours of treatment focusing on communication, language, and social interaction per week (NRC, 2001). Traditional speech-language services for young children with ASD target expressive and receptive language as well as social communication in 1:1 setting, but due to financial and geographic constraints, fewer than 1/3 of parents of children diagnosed with ASD report achieving the 25 hours of intervention recommended by the NRC (Hume, Bellini, and Pratt, 2005; Boisvert, Lang, Andrianopoulous, and Boscardin, 2010).

One approach commonly used to address this disparity is parent training. Previous research indicates that comprehensive parent training that focuses on teaching evidence-

based developmental and behavioral interventions improves child language outcomes (Drew et al., 2002) and social interaction (Aldred et al., 2004; Mahoney & Perales, 2003). By training caregivers to carry-out naturalistic play/routine-based interventions, children can receive therapy consistently throughout the day, and more feasibly achieve the recommended 25 hours of services addressing speech, language, and communication.

A study conducted at the Child and Adolescent Services Research Center indicates that parent training programs that involve parent-clinician collaboration in developing targets and intervention implementation strategies results in reduced parental stress and increased confidence (Brookman-Frazee & Koegel, 2004). However, much of the work completed to date in the area has been conducted under ideal conditions in controlled research settings.

The present study aims to examine parental outcomes following an 8-week parent training intervention completed at the University of Texas Speech and Hearing Clinic (UT Project SKILLS) and describe changes in parenting stress following intervention given in the context of a real-world clinical setting. Participants were not charged to attend sessions, but they did not receive any further incentives. Participants were not disqualified due to lack of attendance, but rather the curriculum was adapted to cover as much information as possible in the allotted time frame.

The current paper will begin with a literature review outlining the critical components of the study: stress theories, family theories, autism, and parent training interventions and then answer questions about parenting stress before and after receiving parent training targeting social communication and language skills for children with autism aim to answer the following questions:

- How do parents of children with autism spectrum disorder participating in UT Project SKILLS describe parenting stress?

- Do parents of children with autism who have completed UT Project SKILLS report a change in stress from pre-intervention levels?

Chapter 2: Literature Review

THEORETICAL FRAMEWORK

Stress

In recent years, there has been a shift in health care paradigms away from the biomedical model of health to the biopsychosocial model of health (WHO, 1946). This model emphasizes the role that psychological and social factors play in an individual's physical and mental well-being. The model suggests that psychosocial stressors can have a profound impact not only on an individual's mental health but also on his or her short and long-term health outcomes. The following is an examination of the literature in the fields of medicine and health psychology, which explores the relationship between stress, resilience, and health.

A study published in the *New England Journal of Medicine* evaluated individual susceptibility to develop a cold virus following exposure to nasal drops containing the virus based on self-reported stress levels (Cohen, Tyrrell, & Smith, 1991). The researchers studied 394 healthy subjects by exposing the participants to cold viruses, placing them in quarantine, and measuring the rate at which participants displayed symptoms. Participants who rated themselves as high stress were 20% more likely to develop cold symptoms than participants who rated themselves as low stress.

While Cohen's cold study was among the first to empirically examine the relationship between stress and physical health in humans, the work has since been extended across many domains of physical health. Self-reported responses to questions targeting stress levels can predict an individual's likelihood of developing minor illnesses such as the aforementioned cold and major health problems including cardiovascular diseases (Cohen, Janicki-Deverts, & Miller, 2007). It is important to acknowledge that

stress, in this case, includes everything from major stressors (e.g., death) to minor hassles (e.g., traffic). Even small daily stressors can affect stress hormones and suppress an individual's immune system (DeLongis, Folkman, & Lazarus, 1988).

The most widely used model for examining stress response is known as the general adaptation syndrome (GAS). Medical doctor and researcher, Hans Selye, created this model in 1946 following his work with hormones and rat sickness. Dr. Selye injected rats either with a hormone that he hypothesized to cause disease or with a placebo solution. To his surprise, he found that rats from both groups developed the same sickness. He concluded that it was the experience of injection and handling that was causing the disease, not the hormone itself (Selye, 1946). Selye was the first person to move the term *stress* from the field of mechanics, where it described matter under pressure, to the field of psychology.

The general adaptation syndrome (Figure 1) is a three-phase model of stress response. The idea is that stress creates a change from baseline (homeostasis), thus changing the way the body normally functions. The three phases include *alarm*, *resistance*, and *exhaustion*. Selye used the terms *general*: “because it was produced only by agents which have a general effect upon large portions of the body,” *adaptive*: “because it stimulated defense and, thereby, helped in the acquisition and maintenance of a state of inurement,” and *syndrome*: “because its individual manifestations are coordinated and, even partly, dependent upon one another” (Selye, 1976; Rice, 2012). This means that stress can be caused by a number of factors and affect the body on a general level by triggering defense mechanisms and physiological responses, which are coordinated with other defense mechanisms and responses. This response to stressors elevates the body's normal resistance level, thereby depleting its ability to resist disease processes.

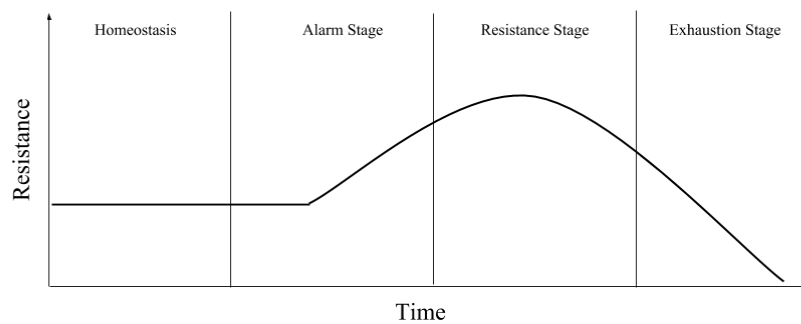


Figure 1: Selye's General Adaptation Syndrome

The first stage of the GAS is *alarm*. During this stage, an individual encounters a stressor, which triggers a fight or flight-like reaction. Symptomatically, a person may complain of increased heart rate, headaches, or cramping (Rice, 2012). In this stage, resistance drops below baseline. However, the person experiencing the stressor rapidly enters the stage of *resistance* in which he or she enacts opposition to the stressor and the symptoms related to alarm disappear. Physiologically, individuals in the resistance stage experience changes at the cell and tissue level that are characteristic of survival defense mechanisms (Rice, 2012). If during the resistance stage the individual does not return to baseline (normal) resistance level, he or she will enter a third stage known as *exhaustion*. In exhaustion, the endocrine system is hyperactive and cortisol levels are elevated. Heightened cortisol levels can result in negative effects on the circulatory system, digestion, and the immune system, making the individual more susceptible to negative health outcomes (Rice, 2012). The work done in the area of health psychology and medicine indicates a need for stress management and prevention and attention to resilience.

Resilience can be defined as the ability to recover from negative or stressful situations and return to normal functioning (Rutter, 1985). An individual's resilience depends on the following five factors: coping, control and self-efficacy, social relationships, dispositions and emotions, and stress management (Hooker & Pressman,

2018). Each of these five factors contributes to resilience and, ultimately, health risk and outcomes.

Coping mechanisms can be either problem-focused or emotion-focused. Problem-focused coping strategies are action-oriented and related to problem-solving in the long-term. Contrastingly, emotion-focused coping strategies target the emotions that accompany stressors (e.g., taking one's mind off of something). Problem-focused coping mechanisms tend to have the greatest effect on mental health and wellness over time. Emotion-focused coping mechanisms play a larger role in things that are outside of one's control (e.g., grief). It is important to be able to match the coping mechanism with the stressor (Hooker & Pressman, 2018).

The next factor of resilience is *control and self-efficacy*. The sense of perceived control over a stressful situation leads to increased resilience and performance on tasks (Glass & Singer, 1972). Similarly, self-efficacy, or the belief that one can perform adequately on a given task, affects individual abilities to achieve goals. Both control and self-efficacy have been shown to improve health and reduce stress (O'Leary, 1985; Hooker & Pressman, 2018). For example, senior citizens living in an assisted living facility who were given a sense of control over their environment (e.g., responsibility for watering a plant) lived longer and healthier lives than residents who were not given the same sense of control (Rodin & Langer, 1977).

Additionally, an individual's *social relationships* may both positively and negatively impact his or her resilience. A meta-analysis compositing the results of more than 308,000 individuals followed for an average of 7.5 years displayed that social isolation has negative impacts on health and places mortality risk factors comparable to regular smoking and exceeding physical inactivity (Holt-Lunstad, Smith, & Layton, 2010). The results of this study highlight an individual's need for social integration and support.

Not all factors of resilience are as easily manipulated. In fact, *disposition and emotions* can contribute greatly to the amount of resilience an individual displays. Individuals with Type A personalities (hostile and competitive) tend to have less resilience than those with Type B personalities. Likewise, positive emotions and optimism tend to co-occur with longevity and improved coping strategies (Hooker & Pressman, 2018).

The final resilience factor is *stress management*. Many Americans report experiencing stress. Furthermore, they report the sources of stress as things that are often difficult to change (e.g., finances, current job, etc.). A variety of stress-management techniques have been introduced in the past ten years, with many as simple as a healthy diet and regular physical exercise (Hooker & Pressman, 2018).

A review of the literature in the area of medicine and health psychology indicates a strong relationship between stress and physical and mental well-being and emphasizes the role of resilience in preventing negative health outcomes. It is important health care providers and therapists are aware of the risk factors associated with high stress levels and low resilience. Raising service providers' awareness may promote identification of high-stress individuals, consideration of client's concerns about stress, referral to mental health services, and an added focus on improving resilience within the provider's scope of practice.

Families

Traditionally, *family* has been defined as a blood, marriage, or adoption relation between two or more people (Murdock, 1949). However, the modern idea of family takes many different forms due to changing social norms such as divorce and re-marriage, same-sex couples, and other variations (Muraco, 2018). Regardless of how one's family presents, there are two predominant camps that describe the close emotional bonds among family

members: attachment theory and family systems theories. In addition to these leading theories, it is important to address the transactional model of development, which suggests that all interactions between people and the environment (including between family members) affect development.

In the 1940s, British psychoanalyst, John Bowlby developed the original idea of *attachment theory* when he observed infants in distress after being separated from parents (Fraley, 2018; Bowlby, 1969). An important extension of Bowlby's work came from Harry Harlow in his famed monkey studies (Harlow, 1958). In these studies, Harlow placed monkeys in cages with "surrogate mothers." These "mothers" consisted of contraptions made of wire and a feeding tube that permitted the researchers to deliver milk or not deliver milk. One "mother" was covered in cloth and the other was not. Harlow discovered that the monkeys preferred the cloth-covered surrogate even when the wire surrogate was providing food, implying that attachment is based in more than the provision of basic needs. Harlow coined the term "contact comfort" and deemed it an important component in establishing infant-caregiver bonds (Harlow, 1958). Harlow's work supported Bowlby's idea of attachment theory emphasizing the relationship between the infant and the caregiver.

Later, Bowlby posited the argument that the child assesses his or her environment on an ongoing basis to determine proximity, accessibility, and attentiveness of the primary attachment figure. He suggested that children feel secure, loved, and confident when all three conditions are met. His research indicated that these feelings translate to social and play behaviors: when a child feels secure, he or she is more likely to explore and behave socially, but when the child feels insecure, he or she is less likely to engage with the environment and more likely to display anxiety (Fraley, 2018; Bowlby, 1969).

Bowlby's work laid the foundation for attachment theory, which was further examined by psychologist Mary Ainsworth. Ainsworth noticed individual differences among infants and hypothesized that Bowlby's basic dynamics cannot be applied to all infants. She systematically investigated attachment and determined that there are three types of attachment exhibited by infants: secure attachment, anxious-resistant attachment, and avoidant attachment (Figure 2) (Fraley, 2018; Ainsworth, Blehar, Waters, & Walls 1978).

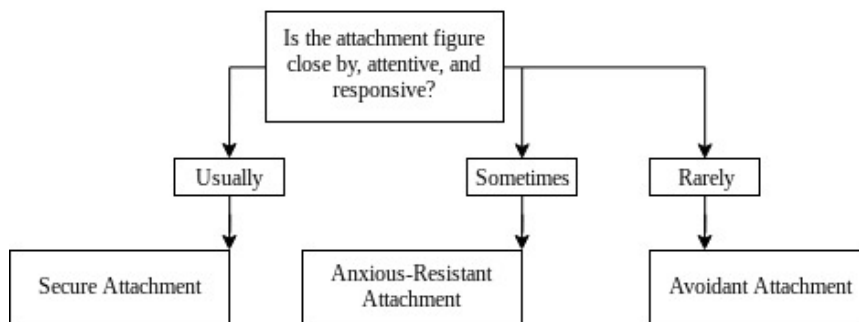


Figure 2: Attachment model (Ainsworth)

In Ainsworth's work, most infants (60%) demonstrated secure attachment and, when separated from their parents, respond as Bowlby predicted. Specifically, these infants showed signs of distress when the parent left and were easily comforted upon return. 20% of the infants she examined showed anxious-resistant attachment. That is, they were extremely distressed when parents left and were not easily comforted upon return. The final 20% of infants showed avoidant attachment. These children did not display stress when the parent left nor did they seek the parent's attention upon return. Furthermore, in her work, Ainsworth demonstrated that attachment patterns correlated with parenting styles. Children with secure attachment patterns tended to have parents who were responsive to their wants and needs and children with anxious-resistant or avoidant patterns tended to have parents

who were more inconsistent or less responsive in their care (Fraley, 2018; Ainsworth et al., 1978).

Other systems of theories that aim to describe familial relationships are family systems theories. These types of theories utilize either macroscopic or microscopic focuses regarding how families interact (Cridland, Jones, Magee, & Caputi, 2014). Macroscopic family systems theories focus on the relationship between family units and the greater environment (e.g., schools, communities) while microscopic family systems theories underscore the importance of how family members relate to each other. While both macroscopic and microscopic theories are important components of family systems theories, the microscopic family systems theories are more pertinent to the present investigation and will be further examined. *Family Systems Theory*, a microscopic iteration, was developed by Murray Bowen in 1978 (Kerr, 2000). According to this theory, each member of the family fulfills a specific role that contains certain rules and expectations. The ultimate goal of each family under this theory is stability. Therefore, when one family member changes roles, the remaining family members must adapt their own rules and expectations must be adjusted.

A key component of Family Systems Theory is the idea of the family as an “emotional unit,” (Kerr, 2000). Family members share an intense emotional connection and profoundly impact other members’ cognitions, emotions, and behaviors. They search for support and approval in the context of their family, and a change in one member’s functioning impacts the entire system. Bowen hypothesizes that the high degree of interdependence is a result of evolution. Families are expected to care for and protect their members. This strong bond is not always positive, however. According to Bowen, increased anxiety among members can result in family distress and potentially lead to one or more members feeling overwhelmed or isolated. This intense feeling may result in an

individual “absorbing” the anxiety of the family system, making him or her vulnerable to developing physical or mental health problems (Kerr, 2000).

Both attachment and family systems theories have shaped the way psychologists think about development and family dynamics as well as how they treat mental health disorders. Though, the examination of the theoretical framework for family systems and attachment is not complete without consideration of the transactional model of development (Sameroff, 2009). This model suggests that child development is the result of continuous exchanges between the child and his or her environment and family. Within this model, interactions between the child and the caregiver are *bidirectional*, which implies that even infants’ behavior influences adult actions. Therefore, while the parent influences the child’s development, the child simultaneously influences the parent (Sameroff, 2009).

Utilizing these three theoretical models, one can begin to understand how a child develops social and emotional relationships within families. Attachment theory describes how a child relates to his or her family members (and later friends and romantic partners), family systems theory emphasizes the unique and interconnected role that the child plays within the family, and the transactional model of development describes how children impact others in their social world.

Consideration of the theoretical framework for stress and family has clinical implications on intervention methodologies for individuals with disabilities and disorders. Identification of people who are susceptible to high stress can facilitate the inclusion of stress-reduction techniques or referral and potentially improve health outcomes. Furthermore, awareness of the interconnected nature of the family can promote higher degrees of collaboration across an individual’s social network to give loved ones and caregivers a greater sense of control and self-efficacy in handling stressful situations.

AUTISM SPECTRUM DISORDER (ASD)

Autism is a heterogeneous developmental disability that results in deficits in social skills, communication, and behavior (NIMH). The label “autism” can be attributed to Austrian psychiatrist, Leo Kanner (Adler, Minshawi, Erickson, 2014). Prior to Kanner’s classification, children with autism were diagnosed with childhood-onset schizophrenia. While modern conceptualizations of ASD and schizophrenia are vastly different, the two diagnoses display similar symptoms: limited engagement in social situations, flat affect, lack of social/emotional reciprocity, etc. Kanner and colleagues first noticed some essential differences between the diagnoses. For example, children with autism have developmental delays in early childhood that are not present in schizophrenia. The two disorders have structurally different neuroanatomy: the brains of individuals with ASD tend to have more grey matter than typically developing brains and the brains of individuals with schizophrenia tend to have reduced frontal and temporal lobe sizes. Lastly, Kanner and colleagues noticed that boys are much more likely to have ASD than girls, but the prevalences for schizophrenia are the same across genders, and people with ASD are much more likely to have comorbid intellectual disability (ID) than people with schizophrenia (Adler, Minsawi, Erickson, 2014).

Kanner’s initial diagnostic criteria were originally very specific, but with further research, he refined his criteria to include: extreme isolation, insistence on sameness, and onset prior to two years of age. While Kanner was instrumental in creating the differential diagnosis for autism, he proposed a number of now disproven assumptions (Adler, Minshawi, Erickson, 2014). One of the most famous and potentially detrimental assumptions included Kanner’s observations of child-parent interactions. From his reports about interaction patterns between mothers and children with autism stemmed assumptions about the etiology of autism. Perhaps the most famous assumption was the “Refrigerator

Mothers' etiology (Volkmar and Lord, 1988), which hypothesized that children developed autism as a result of parents withholding affection. While this hypothesis seems feasible based on attachment theory, it does not account for the neurological differences visible in the brain, the presence of ASD with affectionate parents, or the differences between children who are victims of abuse who do not develop autism (Adler, Minshawi, Erickson, 2014).

Since Kanner, there have been many changes in the diagnosis of autism. With the DSM-5 (American Psychiatric Association, 2013) came the removal of the Asperger's syndrome and introduction of a spectrum. The current diagnostic criteria for autism spectrum disorder (DSM-5) include persistent deficits in social communication and restricted and/or repetitive patterns of behavior and/or interests/activities. The DSM-5 mandates that symptoms be present in the early developmental period and result in a significant impact on an individual's functioning (social, occupational, etc.) Furthermore, the symptoms must not be better explained by a different condition (e.g., intellectual disability, Rett syndrome, Fragile X syndrome, etc.).

These broad diagnostic criteria encompass a wide variety of individuals with very different phenotypes. Little is known about the etiology of ASD, but most scientists suspect a genetic component (Huguet & Bourgeron, 2013). The most recent prevalence estimates report that 1/59 children have autism spectrum disorder and that it occurs four times more frequently in boys than girls (Center for Disease Control and Prevention, 2018). Additionally, as many as 94.3% of children with Autism exhibit some form of challenging behavior (Matson, Wilkens, & Macken, 2009). Challenging behaviors may include stereotyped movements, ritualistic behaviors, aggression, disruption, and/or destruction. These behaviors are not socially acceptable, affect an individual's day-to-day functioning, and

may be physically or mentally dangerous to the self or others (Matson, Mahan, Hess, Fodstad, & Neal, 2010).

ASD, STRESS, & FAMILIES

A study published in the *Journal of Mental Health Research in Intellectual Disabilities* examined the prevalence of challenging behaviors between and within individuals with ASD and other disabilities and found that children and adolescents with ASD were more likely to engage in challenging behaviors than both typically developing peers and peers with other psychopathologies and/or developmental disabilities. As one might predict, individuals with severe autism engaged in higher instances and more severe problem behaviors than individuals with mild or moderate ASD (Matson, Wilkens, & Macken, 2009). These behaviors can result in a variety of personal and interpersonal consequences including social isolation, increased risk of mental health disorders (Myrbakk & Tetzchner, 2008), decreased academic outcomes, and/or injury to self or others (Gerow, Davis, Radhakrishnan, Gregori, & Rivera, 2018). Often, the goal of intervention with children with ASD is to replace these problem behaviors with socially acceptable communication behaviors (e.g., requesting, protesting) with an intervention known as functional communication training (Fisher et al., 1993).

Due to the high prevalence of challenging behaviors, one may reasonably suspect that parents of children with ASD experience more parenting-related stress than that of parents of typically developing children. Researchers at the University of Alberta conducted a meta-analysis examining the relationship between parenting stress associated with raising a child with ASD (Hayes & Watson, 2012). The meta-analysis combined the statistical results of 15 studies that examined parenting stress related to raising a child with autism spectrum disorder by comparison to typically developing children or children with

other disabilities (e.g., Down syndrome, cerebral palsy, and intellectual disability). The combined results indicated that parents of children with ASD report significantly more stress than parents of typically developing children and children with other disabilities.

Similarly, researchers at UCLA examined parenting stress as it relates to child behavior problems. It is often assumed that parenting stress and child behavior are transactional, but few studies have looked at this empirically (Neece, Green, & Baker, 2012). The study examined 237 children and their families from 3-9 years old over a seven-year period. 144 participants were typically developing and 93 were diagnosed with developmental delays. Previous research places children with developmental delays at risk for higher incidences of behavior problems and places parents who report high stress levels at risk for negative outcomes (e.g., depression) (Neece, Green, & Baker, 2012). Results of the study displayed that parenting stress and child behavior problems co-varied. This means that parenting stress was both a cause of child behavior problems and a result of child behavior problems, particularly in the early childhood stages. While the occurrence of behavior problems and parenting stress decreased over time in families of typically developing children, parenting stress persisted in families of children with developmental delays (Neece, Green, & Baker, 2012). The findings of this study support those of many others: stress management interventions may be particularly useful in parents of children with disabilities. Furthermore, stress management interventions for parents may result in decreased behavior problems for children.

THE SPEECH-LANGUAGE PATHOLOGIST

Utilizing the theoretical framework examined previously, one could conclude that all disciplines that deal with the assessment and intervention of ASD have a responsibility to consider not only the individual with the diagnosis but all of the people with whom he

or she interacts on a daily basis. According to the American Speech-Language and Hearing Association (ASHA), the speech-language pathologist is responsible for working with individuals with ASD across the lifespan to improve communication skills: expressive-receptive language, speech sound production, feeding, augmented and alternative communication, and social-pragmatic language (ASHA, 2018).

Within the written scope of practice, there is no mandate for utilizing family systems-styled interventions. However, researchers and speech-language pathologists often include family members through counseling, conferencing, and parent or sibling training. A study published in the *Journal of Autism and Developmental Disorders* assessed the indirect effects of parent training on family dynamics (Koegel, Bimbela, & Schreibman, 1996). The researchers compared the outcomes for children and families when parents were trained to administer a naturalistic social and language skill interventions (pivotal response training, PRT) vs. targeted skill interventions. Results of the study indicated that parents who were taught natural language paradigms displayed a more positive affect during training sessions and carried over these interaction styles to daily living. The parents in the PRT training group also demonstrated more positive responses on happiness, interest, stress, and communication style scales (Koegel, Bimbela, & Schreibman, 1996). These results suggest that without directly addressing parenting stress, the communication intervention affected the parent's quality of life in a positive way. By changing the interaction and communication style and giving parents more control over their child's outcomes, the parents in the study experienced reduced stress. Given the theoretical framework for both stress and family systems, one possibility for this change could be an increase in resilience and solidification of individual roles within the family.

Additionally, a study published in the *Journal of Positive Behavior Interventions* compared clinician-directed parent training and clinician-parent partnerships. The

researchers assigned participants to receive parent training that was either structured as professional help where the clinician was the expert teacher and the parent was the learner or as a collaborative relationship where parents were involved in decision making. Results demonstrated that fostering a collaborative relationship positively affects parents and parent-child interactions. Caregivers in the collaborative group displayed lower levels of observed stress and higher confidence than the caregivers in the clinician-directed condition. Similarly, the children were more engaged and displayed more positive affect during interactions with caregivers who were in the collaborative condition (Brookman-Frazee, Koegel, 2004). Again, this aligns with expectations after studying the theoretical framework. That is, interactions and positive behaviors have a transactional effect for both children and caregivers (transactional model of development).

In therapeutic professions, one must acknowledge the common factors model (Lambert & Bergan, 1994). This model emphasizes the role of components of therapy that are shared by all intervention approaches including extra-therapeutic events, the therapeutic alliance, and the placebo effect. First used in psychiatry, the common factors model has been extended to many other clinical fields (Drisko, 2013). While clinicians commonly attribute client success to specific intervention approaches, this model underscores the importance of the relationship between the clinician and the client.

A review of preexisting work in stress, family models, and autism spectrum disorder combined presents clear support for familial involvement in intervention across professional domains. Speech-language pathologists (SLPs) can contribute to familial collaboration through parent training programs. The current evidence suggests that SLPs should create power-balanced parent partnerships to develop goals for the child and train parents to use naturalistic intervention strategies in order to promote positive interactions

and carryover. This intervention style could benefit the family system as a whole as well as reduce the elevated risk for stress-related negative health outcomes.

PROJECT IMPACT

Previous studies examining parent training programs were done under ideal conditions (e.g., biweekly hour-long sessions for 12 weeks). The present study utilizes an adapted version of a collaborative naturalistic parent training program targeting social communication skills in a natural clinic setting or via telepractice. The intervention is based on Project ImPACT (Improving Parents as Communication Teachers) (Ingersoll & Dvortcsak, 2010). Based on developmental science and behaviorism, Project ImPACT included teaching parents to incorporate prompting and reinforcement techniques appropriate for their child's developmental level. The curriculum instructs the clinicians to develop a collaborative partnership with the parents in which they are involved in goal setting and decision making for their child. The prescribed time frame (and the time frame used in Ingersoll's research) recommends one 90 minute training session per week and one 60 minute coaching session per week over a period of 12 weeks (Ingersoll & Dvortcsak, 2010).

The initial evidence of Project ImPACT suggests that children made significant gains following parent training. Furthermore, lower baseline parenting stress was a predictor of the success of the children after 12 weeks (Stadnick, Stahmer, & Brookman-Frazee, 2015). However, the suggested time frame requires long periods of engagement from the parents and children and 24 trips to the clinic in total.

The goal of UT Project SKILLS (Skills and Knowledge of Intervention for Language Learning Success) is to provide free parent training to families of children with ASD in Texas. Project SKILLS adapted the timeframe, and the participants attended seven

individual one-hour sessions and one two-hour group session over eight weeks. This timeline maximized the number of families enrolled in the program and presents a reasonable intervention package for non-research, non-academic settings. Since most research in the area has been completed under ideal conditions, the present study will assess the dose-response relationship between parent-stress outcomes following parent training and aim to answer the following questions:

- How do parents of children with autism spectrum disorder participating in UT Project SKILLS describe parenting stress?
- Do parents of children with autism who have completed UT Project SKILLS report a change in stress from pre-intervention levels?

Chapter 3: Methods

The goal of the present study is to examine parenting stress and report changes in stress before and after a parent-directed intervention package.

PARTICIPANTS

The participants in this study included fifty-six children with ASD and their parents. Participants were enrolled in UT Project Skills at the University of Texas Speech and Hearing Center. Parents of all 56 participants were included to answer the first research question. Of the fifty-six participants, nineteen completed both the pretest and the post-test. These 19 participants' responses were analyzed to answer question two using parametric statistics. Because a convenience sample was used, generalizations to all parents of children with autism should be made with extreme caution.

Participants were parents of children diagnosed with autism or genetic disabilities that result in autism-like communication skills (e.g., fragile x syndrome) aged 1;2 to 17;0 with an average age of 5;9. The age range of the children whose parents completed both the pre-test and the post-test was 2;3-9;5 with an average age of 4;6. There were 18 male children and 1 female child. Six participants engaged in the training via telepractice (Zoom video conferencing) and 13 received in-person training. See Table 1 for detailed information on participants.

Participant	Absences	Child Sex	Child Age	Modality	Language(s)
1	0	M	8;0	Zoom	English
2	1	M	5;10	In Person	English/Tamil
3	0	M	4;11	In Person	English/Russian
4	0	M	8;3	Zoom	English
5	0	M	2;10	Zoom	English
6	0	M	4;11	Zoom	English
7	3	M	6;0	In Person	English
8	0	M	3;10	In Person	English
9	1	M	2;0	Zoom	English
10	0	M	2;0	In Person	English
11	0	M	5;0	In Person	English
12	0	M	9;5	In Person	Spanish
13	0	M	7;6	In Person	Spanish
14	1	M	2;7	In Person	English
15	1	F	3;1	In Person	English
16	1	M	2;9	Zoom	English
17	0	M	2;8	In Person	English
18	0	M	2;4	In Person	English
19	0	M	2;3	In Person	English

Table 1: Participants who completed both the pretest and post-test

PROCEDURES

Permission to participate in Project Skills was obtained from the parents at the University of Texas Speech and Hearing Center (UTSHC). A clinical IRB waiver was issued for the analysis of clinical data. The Parental Stress Scale used in this study was introduced in the posttest phase of the second wave of spring participants in 2018 and continued through the completion of the posttest phase of the second wave of spring participants in 2019. The primary caregiver and recipient of the SKILLS training completed all pretest and posttest survey data. In order to maintain confidentiality, participants responded to a questionnaire on Qualtrics with results that were password protected. Physical files were stored in a locked room in the UT Speech and Hearing Clinic.

Caregivers attended an initial informational group session followed by seven individual sessions, which contained a teaching component and a coaching component. The caregivers were involved in creating goals for their children that were developmentally appropriate and made decisions about how to use trained behavioral techniques. Clinicians coached parents by providing positive reinforcement for the implementation of training techniques and offered suggestions and support. See Table 2 for a detailed breakdown of sessions.

Session	Naturalistic Language Teaching Technique
Group Introduction	Group introduction to project SKILLS
1	Follow your child's lead, imitation, animation
2	Modeling and expanding language
3	Obstruction, balanced turns, communication temptations
4	Review interactive teaching, overview direct teaching
5	Teaching expressive and receptive language
6	Teaching imitation and play skills
7	Summary and review

Table 2: Project SKILLS Session Schedule

MEASURES

In order to examine parenting stress reported by parents of children with autism, the Parental Stress Scale (PSS) was utilized as a pre-post intervention measure. This scale measures emotions and satisfaction with one's role as a parent. It is an 18 item Likert style survey. Psychometric evidence indicates that the scale has both validity and reliability for both mothers and fathers (Berry & Jones, 1995). The parents reflected on the experience of parenting and responded to questions on a five-point Likert scale (strongly disagree-strongly agree).

DESIGN ANALYSIS

The goals of the present study are to (1) describe stress reported by parents of children with autism participating in project SKILLS and (2) measure any changes in stress from pre-intervention levels. To answer the first question, the results of the PSS were

analyzed using descriptive statistics to describe parenting stress reported by parents of children with ASD participating in project SKILLS. Survey responses were coded on a 1-5 scale where 1 = strongly disagree; 2 = disagree; 3 = neutral; 4= agree; and 5= strongly agree, with higher scores representing higher reported stress. Eight items were reverse scored to maintain consistency in the interpretation of the scale. For example, a parent who scored question one: *I am happy in my role as a parent*, as a 5 (strongly agree) was reverse scored (6 – 5) to 1 to reflect lower stress. Scores on individual questions were summed to achieve an overall score of parenting stress with a possible range of 18-90.

Inferential statistics were used to answer question two to describe change from pre-intervention levels. Analysis included a two-sample paired t-test using the Statistical Package for the Social Sciences (SPSS) given data from the participants who completed both the pretest and the posttest. Descriptive statistics outlining change in composite score from pre-intervention to post-intervention were also completed for each participant.

Chapter 4: Results

The present study was a pilot study aiming to describe the stress experienced by parents of children with autism involved in a parent-directed intervention. As a first step in answering research aim one, characterizing parental stress, descriptive analyses were conducted on pre-test and post-test data. Descriptive analyses suggest normal distribution of data for both pre- and post-intervention. The results of the tests yielded a skewness of .127 (pre) and -.227(post) and kurtosis of -.416 (pre) and -.503 (post), which permitted for the use of parametric statistics in addition to descriptive statistics. Histograms for pre-test and post-test data are included in Figure 3. The findings for each question are described below.



Figure 3: Histograms

RESEARCH AIM ONE: CHARACTERIZING PARENTAL STRESS

The first research question, *How do parents of children with ASD participating in UT Project SKILLS describe parenting stress?* was answered using descriptive statistics. Nineteen participants completed both the pretest and the post-test, 27 completed only the pretest, and 10 completed only the posttest. 46 parents who completed the pre-test reported an average stress level of 41.36 out of 90 possible with a range of 21-64 and a standard

deviation of 10.207. 29 parents who completed the post-test reported an average stress level of 36.53 out of 90 with a range of 18-51 and a standard deviation of 9.190 (Table 3). The mean score for mothers of typically developing children reported by Berry & Jones, 1995 was 37.1 ($SD = 8.1$) and the mean score for mothers of children with developmental disabilities was 40.1 ($SD = 9.3$). The participants in the present study reported average stress levels within one standard deviation of both mothers of typically developing children and mothers of children with disabilities. Participants who filled out the pretest reported slightly higher stress levels than Berry & Jones' (1995) sample, and the participants who completed the post-test reported slightly lower stress levels than the average reported by parents in 1995. Table 3 contains a breakdown of parental responses to the PSS.

	<i>n</i>	Minimum	Maximum	Mean	Std. Deviation
Pretest	46	21	64	41.36	10.207
Posttest	29	18	51	36.53	9.190

Table 3: Descriptive statistics

RESEARCH AIM TWO: CHANGE IN PARENTING STRESS

To answer question two, *Do parents of children with autism who have completed UT Project SKILLS report a change in stress from pre-intervention levels*, a paired *t*-test was completed using SPSS. Data from the 19 participants who completed both the pretest and the posttest were analyzed. The average pretest stress level was 35.84 ($SD = 10.410$) and the average posttest stress level was 35.47 ($SD = 10.384$). The paired *t*-test yielded a

p-value of .835, which indicated that there is no statistically significant difference between the pretest and the posttest measures in reported stress levels (Table 4).

	<i>n</i>	Mean	<i>SD</i>	Standard Error <i>m</i>
Pretest	19	35.84	10.410	2.388
Post-test	19	35.47	10.384	2.382
<i>T-test, p-value = .835</i>				

Table 4: Paired samples statistics

As a second step in answering this research aim, a change in reported stress level score was calculated by subtracting pre-test scores from post-test scores. Descriptive analyses of the change scores revealed three patterns of change: participants who reported lower stress ($n = 9$), participants who reported no change ($n = 4$), and participants who reported higher stress ($n = 6$). The biggest decrease in stress from pre-intervention levels was -11 ($m = -5$) and the biggest increase in stress was +11 ($m = 6.3$).

Chapter 5: Discussion

Prior research in the area of ASD, parent training, and parental stress has been completed under ideal circumstances in controlled research environments (Brookman-Frazee & Koegel, 2004; Moes, 1995; Tonge et al., 2006). The present study is a pilot study extending previous work by examining parental stress into a clinic-focused setting during UT Project SKILLS. The primary emphasis of Project SKILLS was to provide training to parents. The present study presents an analysis of clinical data obtained during the project. Therefore, no participants were excluded from analysis on the basis of attendance, ethnicity/gender, language, socioeconomic status, or treatment modality. Findings and implications from the current study are discussed in the subsequent paragraphs.

SUMMARY

A review of the literature pertaining to stress, families, and autism indicates a need to address parental stress as it relates to parenting a child with autism spectrum disorder (Hayes & Watson, 2012; Neece, Green, & Baker, 2012). Research in health psychology suggests that people who display chronically high stress levels are more prone to diseases (Cohen, Tyrrell, & Smith, 1991; Cohen, Janicki-Deverts, & Miller, 2007). Furthermore, parents of children with autism display significantly higher stress levels than parents of typically developing children (Hayes & Watson, 2012). This difference in stress may be viewed through the framework of attachment theory or family systems models (Bowlby, 1969; Kerr, 2000).

One way to mitigate this risk is to focus on developing resilience (Hooker & Pressman, 2018). UT Project SKILLS indirectly addresses a number of factors of resilience including control and self-efficacy, social relationships, and problem-focused coping mechanisms (Hooker & Pressman, 2018) through a parent-directed intervention. The

project provides parents with tools to implement naturalistic language intervention in the home (control and self-efficacy), creates a clinician-parent partnership (social relationships), and urges parents to take action to address a stressor (problem-focused coping). The goals of the present study were to answer the following questions:

- How do parents of children with autism spectrum disorder participating in UT Project SKILLS describe parenting stress?
- Do parents of children with autism who have completed UT Project SKILLS report a change in stress from pre-intervention levels?

RESEARCH AIM ONE: CHARACTERIZING PARENTING STRESS.

Based on previous work, the hypothesis for aim one was that parents of children with a diagnosis of ASD would report higher stress levels than parents of children without disabilities. However, the results of the current study do not support that hypothesis. The participants reported stress levels that are commensurate with what is expected for any parent when compared to the sample from Berry & Jones, 1995. Explanations for these responses may include positive dispositions, strong family systems, and tendencies to utilize problem-focused coping strategies.

The most static factor of resilience is disposition (Hooker & Pressman, 2018). If the parents who participated in this study have positive dispositions, it is possible that they experience less stress than parents with negative dispositions. Project SKILLS demands openness and vulnerability of the parents. Parents are required to try new strategies that may not feel intuitive or natural (e.g., limiting questions, following the child's lead, and using animation). Therefore, it may be more likely that the participants in the study are more laid back, open to constructive criticism, and aligned with other Type B personality characteristics. This contrasts with individuals who display Type A personalities who value

control and competition (Hooker & Pressman, 2018). Further research indicates that positivity tends to co-occur with improved coping strategies and overall health (Pressman & Cohen, 2005).

Research in family systems theory suggests that families operate as an “emotional unit” in which members protect one another (Kerr, 2000). Kerr proposed two possible outcomes for family systems. The first outcome is a high degree of interdependence and supportive, strong bonds. The second outcome involves one family member absorbing the stress of the entire system. One might expect the second outcome in high stress situations such as receiving an autism diagnosis. However, if the Project SKILLS participants displayed strong family systems that were supportive and cooperative, it may be possible to avoid this result according to the model. Furthermore, it is possible that the parent who absorbed the stress of the system was *not* the parent who completed the survey as only one parent completed the PSS.

Lastly, the participants in Project SKILLS are all inherently engaging in problem-focused coping strategies simply by seeking out the services. Evidence suggests that problem-focused coping strategies that are action-oriented have positive effects on mental health and wellness (Hooker & Pressman, 2018). Given the small sample size, it is possible that all of the families who completed Project SKILLS regularly engage in problem-focused coping strategies and therefore present with resilience and low stress.

The aforementioned factors explain why parents participating in project SKILLS may have reported unexpectedly lower stress levels than the sample of parents in Berry & Jones (1995). Again, without a control group, it is impossible to compare participants’ parenting stress with the stress experienced by parents of typically developing children. It is possible that the discrepancy still exists, but on a smaller scale with parents of both children with and without disabilities experiencing lower stress levels than parents in 1995.

Furthermore, the present study included both mothers and fathers while Berry & Jones (1995) only included mothers.

RESEARCH AIM TWO: CHANGE IN STRESS

UT Project SKILLS is a parent-directed intervention. Therefore, one goal of the project is to support parents and increase self-efficacy while simultaneously improving social communication outcomes for the child. Previous work has indicated that providing parent training can result in parents feeling in control of their environment and reporting lower stress levels (Brookman-Frazee & Koegel, 2004; Moes, 1995; Tonge et al., 2006). The statistical analysis of Likert scale data indicated no statistically significant differences in stress reported by parents participating in Project SKILLS from pre to post-test. Therefore, the study does not confirm the hypothesis that participants in UT Project SKILLS will report lower stress levels following completion of the intervention. This could be explained by the low number of sessions (seven), treatment modality (in person vs. video conferencing), or clinician factors. A close look at each individual participant, however, yielded three distinct patterns of change: increased stress, no change in stress, and decreased stressed. There were no statistics run to indicate *why* these patterns emerged. These results stand in contrast to previous studies in which parents overwhelmingly reported decreased stress following parent training. A number of possibilities may explain this discrepancy including extraneous variables, autism severity, and clinician factors.

Extraneous variables could explain why some participants reported increased stress following intervention. Any number of outside factors could have contributed to parents reporting more stress. Some parents were referred to the project immediately following diagnosis. It is possible that between the administration of the pretest and the post-test these parents' stress levels increased as they learned more about the diagnosis. Other potential

undocumented extraneous variables could include family variables (e.g., divorce, problems with a sibling), environmental variables (e.g., financial issues), and intervention variables (e.g., attendance, treatment modality, language of intervention).

Parents reported if their child had an autism diagnosis, but did not expand upon the severity in the survey collected for the project. Previous parent training programs have controlled for symptom severity (Drew et al., 2002). The present study included participants of all ages and symptom severity levels. Often, severity of autism correlates with increased problem behaviors and subsequently increased parenting stress (Moes, 1995). Furthermore, communication intervention has been effective in decreasing problem behaviors by replacing them with more appropriate communicative actions (Moes, 1995; Fisher et al., 1993). This could potentially explain why some parents reported no change in parenting stress. If the child's baseline symptom severity is low and he or she exhibits low levels of problem behaviors, it is possible that there is no room for large changes in behavior over the seven-week period. Contrastingly, if a child has relatively high levels of problem behavior and the parent training intervention effectively reduces these levels of problem behavior, parenting stress may reasonably decrease.

Lastly, clinician factors may play a role in treatment efficacy. One of the core principles of the intervention involves forming a parent-clinician partnership (Ingersoll & Dvortsak, 2010). The purpose of this is to increase parental self-efficacy and to create a meaningful relationship for the parent. Again, self-efficacy and social relationships contribute to resilience and decrease stress (Hooker & Pressman, 2018). In the fields of psychology and other therapeutic professions (e.g., speech therapy), it is always important to acknowledge the common factors model. This model highlights the role of components of therapy that all interventions share: extra-therapeutic events, therapeutic alliance, and placebo/expectancy (Lambert & Bergan, 1994). This model was first utilized in the field

of psychiatry and then extended into other fields (Drisko, 2013). Modern-day speech-language pathology heavily emphasizes specific intervention strategies, and while parent training programs for social communication have been shown to be effective (Koegel, Bimbela, & Schreibman, 1996; Drew et al., 2002; Aldred et al., 2004; Mahoney & Perales, 2003), the relationship between the clinician and the client must not be discounted. The clinicians at the University of Texas Speech and Hearing Center were comprised of cohorts of first-year graduate students that varied each semester. Since each participant had a different graduate student clinician, the development of parent-clinician partnerships may vary among participants.

LIMITATIONS

The present study is a pilot study examining the role of parent training on parenting stress for parents of children with autism spectrum disorder. It is a brief overview of a complex issue that has many methodological limitations given its clinical nature. The most important limitations are the presence of extraneous variables and the lack of a control group, which prevents generalization of the results to broader populations. The lack of a control group prevents the characterization of parenting stress reported by parents of children with autism compared with parents of typically developing children. Another limitation of the study is the demographic makeup of the participants. While the children enrolled in Project SKILLS were racially and economically diverse, the children of the participants who completed both the pretest and the post-test were overwhelmingly male (18/19). Therefore, any confounding variables that exist in parenting boys vs. girls could not be ruled out of the study. The final limitation of the study involves the large number of clinicians. Since the project was completed over four different semesters at a university clinic, most participants had a different clinician. While all clinicians adhered to the same

curriculum, it is impossible to assess clinician effectiveness at building a partnership with parents with the present data. This limits the ability to discount clinician factors as an agent of change.

IMPLICATIONS

The results obtained answering question one: *how do parents participating in project SKILLS describe parenting stress?* emphasize the need to further examine and address parental stress. In a clinical situation, professionals should include an examination of parental stress beginning with the initial clinical interview. Participants in the present study reported variations in stress ranging from low stress to high stress. Therefore, clinicians must not assume the relative levels of stress experienced by parents of children with autism. Project SKILLS is a parent-directed intervention program in which the parents are involved in treatment and goal setting. Since parents are instrumental to the success of the intervention, it is equally as important that clinicians are aware of the parents' experiences in addition to the experience of the child to personalize the intervention. This project illustrates an example of a practical starting point to target the family as a whole.

Results from the second research aim: *do parents report a change in stress after completing UT Project SKILLS?* were highly variable with parents reporting a wide range of differences from pretest to post-test. This suggests that clinicians should be cognizant of parenting stress associated with raising a child with autism on an ongoing basis. It is unsafe to assume that parent training alone will be effective in changing stress related to parenting a child with ASD. Examination of the literature in attachment and family systems (Bowlby, 1969; Ainsworth, 1978; Kerr, 2000; Sameroff, 2009) can heighten clinician awareness of family members who are at risk for chronically high stress levels, which can lead to poor

health outcomes if not addressed (Cohen, Tyrell, & Smith, 1991). The present study does not negate previous work that found parent training effective in reducing parenting stress (Moes, 1995), but it also displays a potential need for referral as parent training in the clinical setting was not sufficient in reducing parenting stress for all parents.

DIRECTIONS FOR FUTURE RESEARCH

The present study offers a replicable intervention program and provides an outline for well-designed studies to characterize parental stress and to measure change in stress following intervention implementation. Furthermore, it prompts many questions for future research and highlights potential extensions of this work.

Characterizing parenting stress

In order to effectively characterize parental stress, future research should include a control group of parents of age-matched typically developing children. This would allow for a comparison of the stress levels experienced by parents of children with autism to those experienced by parents of typically developing children. Initial participant evaluation should include quantitative data on autism severity and information on parental factors (e.g., mother/father, age, ethnicity, SES, etc.). Including these participant-specific variables would allow researchers to examine correlations among potential confounds and better identify groups of people who may be at risk for experiencing higher stress levels. Furthermore, implementing a qualitative interview may provide more information to better characterize parenting stress and to examine patterns that may not be evident using an 18-item scale.

Change in stress

The efficacy of parent-directed social communication interventions in decreasing parenting stress may be examined by limiting the number of clinicians administering the intervention to reduce variability in the development of parent-clinician partnerships. Periodic conversations with parents about parenting-related stress should be conducted and documented to note the potential influences of extraneous variables. Examination of responses on the parental stress scale in conjunction with autism severity and behavioral changes exhibited by children may indicate the role that maladaptive behaviors (and their reduction) play in changing parenting stress.

Extensions

Possible extensions of this research can examine the implications of training siblings as peer mentors on family systems. It could also examine the effectiveness of training on stress reduction in different settings. For example, does training teachers to utilize naturalistic language intervention strategies during educational instruction affect teacher stress?

If a change in stress is observed after training parents in clinical settings on subsequent research, the logical next step is to closely examine *why* the change occurs. Hypotheses from the current study suggest that change in resilience may reduce stress or change in attachment from either anxious-avoidant or anxious-resistant to secure attachment may positively impact the family system (Hooker & Pressman, 2018; Bowlby, 1969; Kerr, 2000). One could examine this by separating components of the treatment package to determine which parts are effective in improving parental stress levels.

CONCLUSION

Parents of children with autism report more stress on average than parents of typically developing children and parents of children with other disabilities (Hayes & Watson, 2013). This is attributed to the high prevalence of children with autism who exhibit challenging behaviors (Matson & Macken, 2009). One way to reduce challenging behaviors in children with autism is through increasing communication skills (Fisher et al., 1993). The National Research Council (NRC) advises that parents of children with autism receive at least 25 hours of therapy per week (NRC, 2001). One way to increase the number of therapy hours children are receiving is by training parents to implement naturalistic communication strategies in the home. Previous work has suggested that giving parents the self-efficacy to take control of the situation may result in decreased parenting stress (Tonge et al., 2006).

The current paper aimed to extend this work into a clinical parent training program at the University of Texas during Project SKILLS. Results indicated variability in parent-reported stress before and after the training and highlighted a need for future research to examine why these changes occurred. It is important for clinicians to be aware of the risk factors of chronic stress and the stressors related to parenting a child with autism. Furthermore, clinicians should recognize the role of resilience in decreasing parenting stress and build meaningful parent-clinician partnerships to treat the child as he or she operates within his or her family system. Speech-language pathologists should recognize when referral to psychology may be warranted for parents.

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